



ECHO

Extreme Care, Humane Options

Community Recommendations for Appropriate, Humane Medical Care for Dying or Irreversibly Ill Patients

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**SACRAMENTO
HEALTHCARE
DECISIONS**

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Community Recommendations for Appropriate,
Humane Medical Care for Dying or Irreversibly Ill Patients

Introduction

Development of these recommendations

This document is the result of a multiyear, inter-organizational project called Extreme Care, Humane Options (ECHO) under the direction of Sacramento Healthcare Decisions (SHD), a nonprofit, nonpartisan community organization. This is based on the work of three multidisciplinary clinical committees composed of local physicians and other healthcare professionals, and the views and values of local citizens. Information on ECHO and those who participated is included in the appendix.

Expectations for hospitals and other providers

The ECHO Steering Committee urges acute care hospitals in Sacramento, Yolo, Placer and El Dorado counties to adopt the Goals and Strategies included in this document and establish plans to prioritize and implement these strategies.

The relationships among hospitals, physicians, long-term-care settings and health plans necessitate a cooperative approach for the successful implementation of these recommendations. The section Roles of Other Key Healthcare Providers proposes specific actions for these groups.

Cure-oriented vs. comfort care

Medical interventions for dying or irreversibly ill patients can be described as either cure-oriented care or as comfort care. Specific procedures may fall into either of these categories. The distinction between them lies in the *purpose* of the intervention.

Cure-oriented interventions are those with the primary purpose of attempting to achieve a cure, reverse or stabilize the disease process, or bring about a meaningful and measurable improvement in the health status of the patient. These are often invasive procedures such as dialysis, ventilators and cardiopulmonary resuscitation (CPR) but may also include less invasive interventions such as intravenous hydration, antibiotics and diagnostic tests.

Comfort care (or palliative care) interventions have the primary purpose of alleviating distressing physical symptoms and addressing psychological, social, emotional and spiritual needs associated with the disease process. The goal is a more comfortable existence without prolonging the dying process or aggressively sustaining a quality of life that would be unacceptable to the patient. Comfort care may include invasive interventions (such as transfusions, surgery, radiation) for pain or other symptoms. More often, comfort care uses less invasive methods to support the patient's physical and emotional well-being, such as medication, physical therapy and relaxation techniques, counseling and spiritual guidance.

Table of Contents

| | |
|---|---|
| Introduction | 1 |
| Goals and Strategies for Acute Care Facilities | 3 |
| Indicators for Offering Comfort Care | 5 |
| Roles of Other Key Healthcare Providers | 6 |
| Improving Communication About Treatment Decisions | 8 |

Appendices:

| | |
|--|----|
| Appendix A: Overview of the ECHO Project | 13 |
| Appendix B: ECHO Committees | 15 |
| Appendix C: Public Dialogue Groups | 18 |

Principles on which these recommendations are based:

Medical science provides physicians with the means of improving the health and prolonging the lives of most patients. However, interventions are sometimes applied in circumstances or in ways that may not serve the goals of both patients and physicians.

The decision to use medical interventions relies not only on medical science but also on patients' perspectives on quality of life, risk-taking and what constitutes beneficial care. Goals and values of patients and their families

are fundamental to decisions to accept or refuse medical treatment. Healthcare providers also have goals, values and professional standards that guide their recommendation of treatment options. Central to ECHO is the belief that medical treatment decisions should involve a mutually respectful partnership among the patient, family and healthcare team.

*Note: For the purpose of this document, the term **patient/surrogate** refers to whoever is considered the patient's decision-maker. This could be the patient, the family, a legal guardian or conservator, or a significant other.*

The principles underlying the ECHO recommendations

Patient autonomy

The right of self-determination includes the right of competent adults to choose among appropriate treatment alternatives and to refuse any treatment offered. To exercise this right in a meaningful way, patients/surrogates must have the necessary information and the opportunity to make an informed decision.

Avoiding harm

Aggressive, cure-oriented treatment may constitute a *harm*, unless the medical benefit to the patient is apparent, is congruent with the patient's goals and outweighs the burden to the patient. When cure is no longer possible and either death is imminent or a profoundly diminished condition unacceptable to the patient is expected, healthcare professionals should not recommend procedures that increase patients' pain and suffering.

Benefiting the patient

Providing for humane care that respects the dignity of the patient requires far more than the avoidance of harm. The treatment provided by the healthcare team for those terminally or profoundly, irreversibly ill must be purposefully and conscientiously aimed at meeting the patient's physical, psychological, social, spiritual and emotional needs in an environment of caring and support.

Medical integrity and the goals of medicine

The goal of treatment should be improvement of the patient's prognosis, comfort, well-being, or general state of health, or maintenance at a level of functioning that constitutes a quality of life satisfactory to the patient. There are limits to what medicine can achieve. The physician's recommendation of interventions that have little likelihood of meaningful benefit to the patient may create unrealistic expectations about medicine and the patient's prognosis. It may deprive the patient of peaceful, humane support at the end of life. Nonmedical goals, such as meeting the family's emotional needs, must be recognized and addressed with compassion, while balanced with the principles of responsible and effective clinical practice.

Wise use of societal and personal resources

Medical interventions can be extraordinarily expensive. If treatment can neither maintain nor improve health, nor restore function, it may be both fruitless and wasteful. Though the cost of treatment should not be the primary reason for precluding a treatment option, healthcare providers and consumers have a duty to be wise stewards of communal resources. Likewise, all must be aware of the financial burdens often borne by patients and families.

Goals and Strategies for Acute Care Facilities

GOAL 1:

Develop treatment options that are responsive to the needs of dying or irreversibly ill patients and their families.

Strategies

- 1.1 Incorporate a statement of principles regarding the institution's role in the care of terminally or profoundly, irreversibly ill patients.
- 1.2 Develop and implement comfort care protocols, including procedures for transitioning patients and families from cure-oriented to comfort care and timely referral to hospice.
- 1.3 Provide training for physicians and multidisciplinary staff in the provision of comfort care in all hospital settings.

GOAL 2:

Identify patients at risk of inappropriate or unwanted medical treatment.

Strategies

- 2.1 Adopt and implement **Indicators for Offering Comfort Care** (page 5).
- 2.2 Establish and maintain an ongoing process for reviewing ICU patients for appropriate treatment: cure-oriented or comfort care.
- 2.3 Include in quality-of-care activities evaluation mechanisms for the appropriate use of comfort care protocols, adherence to advance directives, etc.
- 2.4 Sponsor educational programs for health professionals on the identification of at-risk patients and the availability and use of hospice and other community services.

GOAL 3:

Improve communication among patients, families, physicians, other healthcare team members and healthcare settings in order to foster informed, timely and mutually satisfactory treatment decisions.

Strategies

- 3.1 Define expectations for communication about end-of-life care.
- 3.2 Train healthcare personnel in communication about end-of-life care, which takes into account cultural and religious differences.
- 3.3 Initiate institutional changes for eliciting, documenting and sharing relevant information among patient/surrogate, primary care physician, specialists, other healthcare professionals and between acute and long-term-care settings.
- 3.4 Provide emotional support/grief counseling for patients, families and the healthcare team confronting end-of-life treatment decisions.
- 3.5 Develop materials and training for patients/surrogates and community members concerning their rights and responsibilities in communication about end-of-life issues.

(See **Improving Communication about Treatment Decisions**, page 9)

GOAL 4:

Assure that the patient/surrogate is the primary decision-maker in choosing among appropriate treatment options.

Strategies

- 4.1 Evaluate current presence of, and compliance with, advance directives in patient charts; establish objectives for improvement.
- 4.2 Educate patients/surrogates and healthcare professionals about institutional policies (including the use of the Bioethics Committee) that address ethical concerns about treatment decisions.
- 4.3 Develop and sponsor community education programs to increase public awareness of, and participation in, advance planning for end-of-life decisions.

GOAL 5:

Support effective processes for preventing and resolving conflicts regarding treatment decisions that respect patient values and the professional integrity of healthcare providers.

Strategies

- 5.1 Educate healthcare professionals and consumers about common areas of miscommunication or misunderstanding concerning end-of-life treatment decisions.
- 5.2 Improve the knowledge, skills, visibility and accessibility of the institution's Bioethics Committee.
- 5.3 Improve physicians' understanding of current legal and ethical rights and obligations in providing and withholding life-prolonging treatment.
- 5.4 Explore an open and fair process that considers and resolves physicians' concerns about demands for medically inappropriate care.

Indicators for Offering Comfort Care

Adult patients or their surrogates

If cure-oriented treatment is no longer medically appropriate or desired by the patient/surrogate, then the principle of beneficence obligates the healthcare provider to make comfort care available.

If the patient has not explicitly indicated—verbally, in writing or through a surrogate—a desire to forego cure-oriented treatment, comfort care should nevertheless be considered and discussed with the patient/surrogate if:

- The patient is terminally ill.
- A profoundly diminished quality of life is imminent or has been established as irreversible.

In the following circumstances, comfort care must be offered as an option:

1. Persistent vegetative state
2. Minimal cognitive function (absence of self-awareness or awareness of others) that is irreversible
3. The burdens to the patient of cure-oriented treatment are greater than the medical benefit to the patient
4. Irreversible and irreparable (multi) organ failure
5. Imminent demise

Nonviable or irreversibly ill newborns

Advances in medical technology have improved the outcomes of many infants born prematurely or with complex medical conditions. It is now possible to keep devastated newborns alive for long periods of time. An unintended consequence of such treatment is a prolonged dying process for some newborns or the survival of some infants with severely debilitating conditions. Medical treatment of infants should be based on consideration of the benefits and burdens of life-sustaining medical treatment and determination of what is in the infant's best interest. Reaching these decisions through collaboration between the parents and the healthcare team is the goal.

In considering situations where comfort care for the infant may appear to be the most appropriate intervention, physicians must be well informed of changes in medical science. The dynamic nature of medical knowledge may lead to successful interventions for conditions that were previously untreatable. Furthermore, family and medical circumstances may vary greatly between cases, requiring each case to be considered individually. With an uncertain diagnosis or prognosis, cure-oriented treatment is generally indicated. Modifications may be initiated as the physician's experience with the infant increases. In those tragic situations where medical science currently has no effective remedy, it is critical that parents be told so.

Comfort care may be the most appropriate option to offer parents in a variety of situations, such as:

1. Conditions for which life expectancy is severely limited even with aggressive therapy. Current examples include but are not limited to:
 - Profound perinatal asphyxia
 - Prematurity less than 23 weeks and under 500 grams
 - Severe multiple congenital anomalies
2. Conditions for which cognition may reasonably be expected to be absent or profoundly limited. Current examples include but are not limited to:
 - Anencephaly
 - Trisomy 18
 - Trisomy 13
3. Conditions for which morbidity is so great and care is so extremely burdensome to the patient that quality of life is severely impaired. Current examples include but are not limited to:
 - Osteogenesis imperfecta type 2
 - Multisystem organ failure

Roles of Other Key Healthcare Providers

Appropriate end-of-life care is an inter-institutional, interdisciplinary obligation. The goals stated in this document are relevant not only to acute care facilities but also to long-term-care settings, physicians groups, health plans, professional associations, regulatory agencies and others. The interdependence of healthcare providers and settings is such that success in achieving appropriate care for dying patients *requires* a coordinated and cooperative approach.

The ECHO project urges other providers to also commit to goals and strategies that are relevant to their setting or constituency.

Physicians/medical groups

Physicians are increasingly expected to do more for patients in less time, making discussions about end-of-life care more difficult. Physicians are, however, the authorities on realistic and feasible medical treatment options and should not abdicate their role in discussing these issues with patients/surrogates.

Physicians should be responsible for the following:

1. Identify patients most at risk of unwanted or inappropriate medical treatment (e.g., residents in long-term-care settings; those with progressive, incurable conditions) and initiate discussions before a medical crisis occurs.
2. Provide patients/surrogates with clear, understandable information regarding condition, prognosis, treatment options, risks/benefits and potential outcomes.
3. Be familiar with the principles and application of comfort care interventions.
4. Improve their communication skills in discussing end-of-life decisions with patients/surrogates.
5. Involve other members of the healthcare team—nurses, social workers, clergy—to assist with patient/surrogate communication.
6. Provide advance directive materials for patients (e.g., in waiting rooms and other outpatient settings) and include advance directive inquiries on information sheets for new patients.
7. Assess the decision-making capacity of patients.
8. Assure that patients' completed advance directives forms and/or chart notes about patient wishes become part of inpatient medical records.
9. Stay informed on institutional policies, procedures, legal and ethical issues related to end-of-life decisions; consult with the Bioethics Committee to seek advice, as needed.

Long-term-care settings

Existing policies for skilled nursing facilities (SNFs) directly affect when and why terminally or irreversibly ill patients are transferred to and from acute care facilities. These policies—determined by regulatory, financial and logistical circumstances—may impede the provision of comfort care interventions within the SNF setting.

Most of the Goals and Strategies listed previously also apply in long-term-care settings, especially skilled nursing facilities. To assure that these recommendations can benefit SNF patients and their families, the ECHO project recommends that a task force be convened of local and state leaders from the long-term-care industry. This task force should explore existing barriers and propose changes that will facilitate the provision of comfort care in all long-term-care settings and improve communication and coordination between SNFs and other providers.

Health plans and payers

As healthcare systems evolve, there are opportunities to develop new approaches to end-of-life care. Health plans and payers must be responsive to the need to support and strengthen appropriate and humane end-of-life care both within and outside the hospital setting. Consistent with health plans' role in providing member education, information and preventive services, plans should also assume greater responsibility for educating healthcare professionals and consumers about end-of-life care.

Health plans should be responsible for the following:

1. Sponsor physician education seminars on such subjects as:
 - Physician-patient/surrogate communication skills concerning end-of-life decisions.
 - Sensitivity to cultural and religious differences.
 - Comfort care plans including pain management .
 - Ethical and legal standards concerning termination of treatment.
2. Develop mechanisms that encourage physicians to conduct planned and purposeful discussions with high-risk patients (those with progressively debilitating or terminal illnesses) about their values and goals related to end-of-life treatment.
3. Work with community-based organizations in planning and conducting consumer education programs designed to educate the public about advance directives and encourage consumer responsibility for communicating personal end-of-life values.
4. Provide educational tools—e.g., videos, informational booklets, discussion guides—related to end-of-life decisions for use by health plan members, physicians, nurses, clergy and community organizations.
5. Provide advance directive documents for any health plan member upon request.
6. Sponsor educational programs specifically for public and private guardians or conservators acting as medical surrogates.
7. Review health plan benefits to assure consistency in support of the provision of comfort care interventions.

Improving Communication About Treatment Decisions

Improving communication is key to achieving all five goals. In considering the strategies for Goal No. 3, the ECHO project has identified important elements that could be incorporated into policies or procedures.

Adult patients or their surrogates

Identifying and responding to patients who are at risk of non-beneficial or unwanted medical treatment are the responsibilities of the patient's primary physician in conjunction with other healthcare professionals: specialists, nurses, social workers and clergy. A multi-disciplinary approach is recommended. Communication and decision-making among patients, families and providers can be improved by adoption of the following:

A. Elicit and share relevant information

Under the direction of the primary physician (or, when appropriate, the midlevel practitioner), the team has the responsibility to elicit, document and share with other team members relevant information about the patient's values and end-of-life preferences. Others involved with the care of the patient also have the responsibility to share relevant information with team members.

Ideally, planning for future care with the patient/surrogate should take place over time, on a regular basis and as needed by changes in the patient's clinical condition. There may be many opportunities and methodologies for gathering and sharing information.

The healthcare team should be responsible for the following:

1. Provide clear and timely information to the patient/surrogate regarding diagnosis, prognosis, expected level of functioning and extent of medical and social needs required by the patient.
2. Seek to understand the patient/surrogate's goals and expectations.

3. Present treatment options that are congruent with the patient's goals.
4. If cure-oriented treatment cannot be recommended, explain to patient/surrogate the medical reasons for that judgment.
5. Be aware of, and sensitive to, cultural, religious and social differences that may influence the roles which the patient and family play in medical decision-making.
6. To the extent possible, provide patient/surrogate the time needed for making or accepting treatment decisions.
7. Follow established protocols for assessing patient's decision-making capacity.
8. Establish timely and effective mechanisms for receiving and sending advance directives and patient preference information between healthcare facilities and agencies involved in the patient's care.
9. Document clearly the communication held with patient/surrogate about these issues.

The patient/surrogate is always central to decision-making. As such, he or she must be as informed as possible regarding issues related to personal treatment choices and actively participate in communication and decision-making.

Patients/surrogates should be responsible for the following:

1. Discuss end-of-life treatment choices with family members, significant others, clergy and healthcare providers within the context of patients' cultural or religious beliefs.
2. Be receptive and available to the healthcare team for discussing patient's condition, needs, goals, expectations and treatment options.

3. Be proactive in soliciting the involvement of the primary physician in discussing end-of-life treatment options.
4. Alert providers if an advance directive has been completed and provide a copy of the document for inclusion in the patient's medical record.
5. Consider designating one family member to be the main contact with the healthcare team if communication between the family and team is complex.

B. Have sufficient understanding of ethical, legal and institutional policies

Healthcare professionals and patients/surrogates should know, for example, that:

1. Treatment choices may include the option *not* to treat.
2. "Not treating" is not the same as doing nothing; comfort care protocols should be described as a treatment option.
3. The plan of action for the patient can be changed as circumstances change; the option to *stop* treatment may become as important as the option to *start* treatment.
4. There are institutional processes for clarifying ethical or legal uncertainties and to help resolve conflicts between the patient, surrogate and healthcare team.

C. Assure appropriate decisions about terminating life-support in the absence of a competent patient or surrogate.

When the patient is not competent to make his or her own decisions and there are no family members or surrogates who can speak on the patient's behalf, then any decision to terminate cure-oriented management should be reviewed (in advance, when possible) with the institution's bioethics committee or other designated team.

Patients in long-term-care settings can be particularly vulnerable to the inappropriate provision (or withholding) of cure-oriented medical treatment, and a system for patient review should be in place.

Parents of a nonviable or irreversibly ill newborn

Communication with parents is a critically important responsibility of all members of the healthcare team. In order to achieve maximum effectiveness, communication needs to be ongoing, planned and purposeful in nature. The following principles should be incorporated in the policies and procedures for each labor and delivery department, newborn nursery and neonatal intensive care unit:

A. Elicit and share relevant information

The healthcare team should be responsible for the following:

1. Make every effort to reach agreement among the healthcare team before presenting and recommending treatment options to the parents.
2. Keep parents apprised of all aspects of care and treatment of their infant, including treatment options, their consequences and the types of immediate and long-term care needs.
3. As needed, offer assistance to help them understand what the long-term consequences may be for an infant with a devastating condition.
4. Elicit from parents their willingness and ability to care for an infant who will need complex support at home.
5. To the extent possible, provide parents the time needed for making or accepting treatment decisions.
6. If cure-oriented treatment cannot be recommended, physicians should explain to parents the medical reasons for that judgment.
7. Provide emotional support to families and assure parents that their child has value, regardless of decisions made or treatment outcome.

B. Make and reconsider treatment decisions

Healthcare team responsibilities:

1. It is generally better to resuscitate and later forego support if that becomes appropriate, rather than to not provide support initially in situations where:
 - The parents are ambivalent or there is disagreement between the parents.
 - The physician is uncertain about viability.
 - Sufficient time before delivery did not allow a discussion to develop between the parents and physician.
2. Make recommendations only for options that are consistent with sound medical practice.
3. When cure-oriented intervention has been agreed upon, the decision should be revisited:
 - If the infant fails to show the expected response.
 - Whenever there is a significant change in the infant's health status.
 - When a parent or healthcare professional asks for re-evaluation.
4. In the face of new information, everyone should be prepared to alter decisions.
5. Where further discussion is necessary, it is important to continue supporting the infant until areas of controversy can be resolved.
6. When comfort care is offered, it is offered as respectful and compassionate treatment.

The parents are always central in the decision-making process. For parents to make informed decisions, it is important that they be as active as possible in discussions related to treatment choices.

Parents responsibilities:

1. Be available to discuss issues related to the infant's condition, treatment options, their consequences and the types of immediate and long-term care.
2. Be timely in responding to the informational needs of members of the healthcare team.
3. Identify those family members who are the key decision-makers for the infant.
4. Seek assistance from members of the healthcare team when more information is needed.
5. Seek information from community resources to fully understand the support required for a severely impaired child.
6. Be prepared to alter decisions in the face of new information.

Appendices

Appendix A

Overview of the ECHO Project

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Appendix B

ECHO Committees

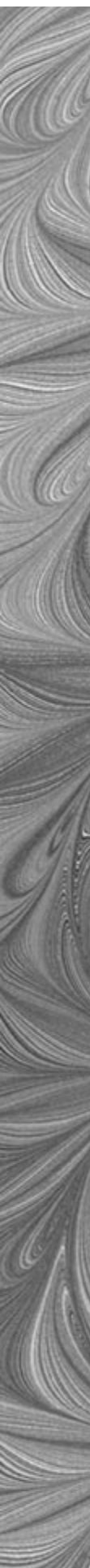
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Appendix C

Public Dialogue Groups

ECHO Moderators





APPENDIX A

Overview of the ECHO Project: 1994–1996

Sponsoring organization

Sacramento Healthcare Decisions (SHD) is a nonprofit, nonpartisan organization committed to involving the public in healthcare policy and practice issues. SHD facilitates communication among healthcare consumers, providers and policymakers. Additional information about SHD or ECHO is available by calling (916) 484-2485.

Project funding

ECHO is funded through a grant from Sierra Health Foundation. Additional support has been provided by Mercy Healthcare Sacramento, Kaiser Permanente Medical Care Program, Sutter Community Hospitals, the California Association of Catholic Hospitals and the Sacramento-El Dorado Medical Society Alliance.

ECHO's collaborative process

Based on SHD's mission that the public's voice must be included in healthcare changes, identifying and incorporating public values was a critical element to this process. Therefore, ECHO emphasized a two-pronged approach: a community-based Public dialogue and a multidisciplinary, inter-organizational clinical dialogue. Under the direction of ECHO's Steering Committee, several components were developed for the dialogues. The final ECHO document merges public and provider perspectives.

Public dialogue

- Ninety-two public discussion groups were held in Sacramento, Yolo, Placer and El Dorado Counties. Led by 52 trained moderators, these two-hour structured, interactive discussions provided 972 residents with the opportunity to discuss the values, priorities and trade-offs they feel are most critical when decisions are made about appropriate end-of-life medical treatment.
- To identify specific aspects of communication and decision-making that arise, a focus group was held with families who had recently experienced difficult end-of-life decisions.
- A 1,022 person random telephone survey was conducted addressing these and related issues, augmenting the discussion groups' qualitative results with quantitative data.

Clinical dialogue

- Three separate, multihospital clinical committees—Adult Intensive Care, Neonatal Intensive Care and Long-Term Care—met for about a year to develop their recommendations.
- A Conflict Resolution Committee was formed to look specifically at the issue of providers' concerns about demands for medically inappropriate care.
- SHD distributed a Physician Survey on End-of-Life Ethics to nine hospitals in the region. With more than 1,300 physicians participating, this survey is a tool for identifying educational needs and encouraging changes in practice.

Communicating and reviewing the results

- A half-day forum, *Seeking Common Ground: Medical Treatment at the Margins of Life*, was held in June 1996, bringing together more than 300 healthcare professionals, policymakers, and community members to hear and comment on the results of ECHO's dialogues.
- A draft version of the ECHO report was reviewed by local bioethics committees; more than 600 copies were distributed on request to local residents and interested healthcare leaders in California and 18 other states.
- The draft report was reviewed and endorsed by the Board of Directors of the Sacramento-El Dorado Medical Society.
- Seventeen community groups were convened to review and discuss the draft document.
- An Education Committee began identifying physician, staff, patient and community needs and opportunities.
- The print and broadcast media reported on ECHO in detail, with substantive coverage in *The Sacramento Bee*, *The Business Journal*, *California Medicine* and other local and state publications.

Project Timeline

| 1994 | 1995-1996 | 1996 | 1997- |
|---|--|---|--|
| Design Project Steering Committee | Conduct Public Dialogue Discussion Groups Phone Survey Family Focus Group Conduct Clinical Dialogue Adult Intensive Care Neonatology Long Term Care | Review Results Community Forum Draft Recommendations Steering Committee Review Recommendations Bioethics Committees Physicians Groups Consumers | Approve and Implement Recommendations Hospitals Other Providers |

APPENDIX B

ECHO Committees

Steering Committee

Fran Alberghini, MSW
Chief, Sac. County Senior & Adult Services
Clifford Anderson, PhD
Professor of Philosophy, CSUS
Vicki Bailey
Hospital chaplain/counselor
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California Association of Catholic Hospitals
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Mercy San Juan Hospital
Byron Chell, JD
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Paul Janke, D. Min.
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Lodi Hospital, Bioethics Comm Chair
Elizabeth Mackenzie
Community member
MJ Nealon, RN, MPH, MSN
Woodland Healthcare, Bioethics Comm. Co-Chair
Ellen Robinson-Haynes, MA
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Glennah Trochet, MD
Medical Director of Clinics, Sac. County
Michael Tscheu, MSW
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Carol Zerbo
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Public Dialogue Committee

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Timothy H. Little, D.Min.
Chaplain, UC Davis Medical Center

Diane McCann, EdD
UC Davis Medical Center (ret.)
Ellen Robinson-Haynes, MA
UC Davis Violence Prevention Research Program
Michelle Schwartz
Berkeley Bioethics Associates
Carol Zerbo
Community member

Staffing

As Project Director, Marjorie Ginsburg participated in and provided staffing for all ECHO committees. Anita Catlin, MSN, FNP assisted with the Neonatology Committee. SHD staff members Kathy Glasmire and Devara Berger, MPA, assisted with other committee work.

Adult Intensive Care Committee

Janet O' Brien MD, CHAIR
Woodland Healthcare
Cathy Burke, LCSW
UC Davis Medical Center
Monique Cesna, CCRN
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Kathy Chetley, RN
Kaiser Sacramento
Howard Grindlinger, MD
Sutter Center for Psychiatry
Sr. Marilee Howard, PhD
Sisters of Mercy, Auburn
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Cheryl Kenner, RN
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Donald Kobrin, MD
Lodi Hospital, Bioethics Comm Chair

Sharon Melberg, RN
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Elsie Flemmer, SW
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Lisa Hoffman, SW
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Henry Kano, MD
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Janie Linck, RN
UC Davis Medical Center
Jay Milstein, MD
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Alta California Regional Center
Susan Ozanne-Warm, CNS
Mercy General Hospital
Peter Pryde, MD
Perinatal Association of No. California
Mark Ziegler, MD
Kaiser Sacramento

Long-Term-Care Committee

Cheryl Franzi, GNP, CHAIR
U.C. Davis Core Faculty
Fran Alberghini, MSW
Chief, Sac County Senior & Adult Services
Jay Anderson
Administrator, Heritage Convalescent
Herbert Bauer, MD
Woodland Healthcare, Bioethics Comm Co-Chair
Jeff Beane, MD
Kaiser So. Sacramento
Susan DeMarois
Calif. Assn. of Homes and Services for the Aging
Donna Fullmer, RN
Marshall Hospital
Bob Hewes, BCC
Chaplain, Sutter Continuing Care

Calvin Hirsch, MD
UC Davis Medical Center
Barbara Johnston, RN
Kaiser Sacramento
Elliot Mazer, MD
MedClinic
Marie Nitz, RN
Gero-Psych Unit, MedClinic
Cheryl Phillips-Harris, MD
Sutter Community Hospitals
Gay Raney, RN
Kaiser So. Sacramento
Karen Walton, LCSW
Corporate Consultant, Eskaton
Carol Zerbo
Community member

Conflict Resolution Committee

Patsy Schiff, JD, CHAIR
Professional Mediator
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Sr. Marilee Howard, PhD
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Charity Kenyon, JD
Diepenbrock, Wulff, Plant & Hannegan
Judge Barry Loncke
Sacramento Municipal and Superior Court
Mary Parks, JD
Medical-Legal Affairs, Kaiser Permanente
Robert Quadro, MD
Medical Director, Mercy Hospice
Howard Slyter, MD
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Sutter Memorial Hospital

Education Committee

Diane McCann, EdD, Chair
UC Davis Medical Center (ret.)
Connie Alward-Mayers, LCSW
Sutter Auburn Faith
Linda Anderson, RN
Sutter General Hospital
Nancy Asmus, RN
Marshall Hospital
Deborah Brady, RN
Mercy General Hospital
Margaret Clausen, CAE
Director, Calif State Hospice Association
Sue Clement, RN
Sutter General Hospital
Horti Davis, RN
Sutter Roseville
Chris Evans, MSN, RN
Mercy Healthcare Sacramento

Jeanine Lewis, RN
Sutter Roseville
Carolyn Morley
Woodland Healthcare, Education Services
Linda Moyle, RN
Kaiser Sacramento
MJ Nealon, RN, MS
Woodland Healthcare, Bioethics Comm. Co-Chair
Deborah Ogrod, RN, MSN
UC Davis Medical Center
Joel Porter, RT
Marshall Hospital
Gay Raney, RN
Kaiser So. Sacramento
Jean Steel
Kaiser Davis and Sacramento

APPENDIX C

Public Dialogue Groups

ECHO Discussion Groups

(October 1995 - March 1996)

Total number of groups held: 92

Total number of participants: 972

Demographics of participants (not every participant completed the demographic form)

| Gender (N= 916) | | Residence (N=920) | | Ethnicity (N=913) | |
|-----------------|-----|-------------------|-----|-------------------|-----------|
| Male | 304 | El Dorado | 49 | Afr. Amer. | 52 (6%) |
| Female | 612 | Placer | 125 | Hispanic | 33 (4%) |
| Age (N=912) | | Sacramento | 553 | Asian | 52 (6%) |
| 18-34 | 135 | Yolo | 147 | Nat. Amer. | 22 (2%) |
| 35-64 | 494 | Other | 46 | White | 740 (81%) |
| 65+ | 283 | | | Other | 14 (2%) |

List of group discussions

Church/religious groups: 38

Atonement Lutheran Church, Rosemont (2)
The Belfry-UC Davis campus ministry
Bethany Presbyterian Church (2)
Bethel Lutheran Church, Roseville
Calvary Lutheran Church, Rio Linda
Community Lutheran Church, West Sac.
Cordova United Presbyterian Church (2)
Davis Community Church (3)
Davis Lutheran Church
El Dorado County Federated Church
ELCA Clergy
Faith Evangelical Presbyterian Group, Folsom
Faith Lutheran Church, Meadow Vista (2)
First Cong. United Church of Christ, Auburn
First English Lutheran Church, Oak Park
Good Shepherd Lutheran Church
Grace Lutheran Church, Rancho Cordova (2)
Holy Family Church Women's Council (2)
Loomis Methodist Church
Lutheran Church
of the Cross
Missouri Synod Lutheran Pastors (2)
Progressive Area
Lutheran Singles
So. Sacramento
Christian Center
St. Andrews AME
St. John's Lutheran Church
Trinity Cathedral
Trinity Presbyterian Church, West Sac. (2)
UCD Chaplaincy Services

Boards/professional associations: 15

Adult and Aging Commission (2)
California Retired Teachers Assn. (5)
Leadership Sacramento (3)
Marshall Hosp. Citizen's Adv. Committee
Mercy Health Ministries members (2)
Public Health Advisory Committee
UCDMC Community Advisory Board

Workplace/volunteers: 13

Asian agencies staff (2)
Sac. Co. Dept. of Health and Human Svcs. staff
Sac. Co. Dept. of Medical Systems staff
CSUS Psychological Services staff
El Dorado County
Health Dept. staff
Kaiser Davis volunteers
Kaiser South Sacramento volunteers
Mercy Folsom Hospital Auxiliary (2)
Resources for Independent Living staff
Sutter Adolescent Family Life Prog. staff
Sierra Health Foundation staff

Education related: 12

CSUS Bioethics class (3)
CSUS MSW Policy class (4)
Golden Gate University graduate students
Sierra College Human Dev. classes (4)

Private homes: 12

Other: 2
Alzheimers Support Group, Placerville
Filipino community group

ECHO Moderators

Fran Alberghini
Sac. Co. Senior & Adult Services

Mary Baker
Private home health RN

Phyllis Bolt
Retired RN, Davis

Louis Bronson
Retired Social Work professor

Maria Carrillo-Shore
Former community clinic administrator

Jan Carter
California Assn. of Catholic Hospitals

Carole Ching
Asian Resources

Sharron Clark
Private home health RN

Gail Conners
Volunteer Services Director, Sutter

Nancy Cullifer
Mercy Folsom RN

Lori Dangberg
Mercy Healthcare Sacramento

Susan DeMarois
California Assoc. of Homes & Services for the Aging

Susan Fossum
UC Davis Medical Center RN

Donna Fulmer
Marshall Hospital RN

Michael Gaddini
Mercy Folsom MD

Kent Gary
Transit Manager, City of Folsom

Bonnie Gieschen
Kaiser So. Sacramento MD

Holly Hindelang
Mercy Folsom RN

Lisa Hoffman
Sutter clinical social worker

Judith Hwang
UC Davis Medical Center MD

Gail Jackson
Marshall Hospital RN

Paul Janke
Inland Area Coordinator, Lutheran Social Services

Lori Jarvis-Steinwert
Sierra Health Foundation

Corrine Joe
Sutter hospital administrator

Henry Kano
Woodland Healthcare MD

Sunita Kapoor
Kaiser Sacramento RN

Diane Keys
Community Services Planning Council

Betty Kirby
Roseville Hospital RN

Mary Anne Kirchner
Volunteer supervisor, Mercy Hospice

Yvonne J. Kochanowski
Business/healthcare consultant, Placerville

Marsha M. Lang
Attorney, consultant

Moroni Leash
Kaiser Sacramento clinical social worker

Sally Liedholm
Public Guardian, El Dorado County

Bill Mason
Retired hospital administrator, Sutter Health

Diane McCann
Health educator

Althea Moynihan
Planning consultant, RN

MJ Nealon
Nursing instructor, Woodland

Judith B. Osen
Community volunteer, Roseville Hospice

Steven M. Paul
Kaiser Sacramento manager

Karyn Piche
Access Health

Stephen Price
Dialysis RN

Gay Raney
Kaiser South Sacramento RN

Susan Roberts
Sutter RN

Adele J. Rothermel
Yolo County Dept. of Social Services

Star Rudge
Omni Health Care RN

Henry Sepulveda
Public administrator, attorney

Howard Slyter
Kaiser Sacramento MD

Marsha Vacca
California Healthcare Association

Heidi Weiland
El Dorado County mediator

Hach Yasumura
Sac. Co. Department of Social Services

Andy Zerbo
Community member, Rocklin

Carol Zerbo
Community member, Rocklin